

Preferred and actual participation roles during health care decision making in persons with cancer: a systematic review

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The preferred and actual participation roles during decision making have been studied over the past two decades; however, there is a lack of evidence on the degree of match between patients' preferred and actual participation roles during decision making. A systematic review was carried out to identify published studies that examined preferred and actual participation roles and the match between preferred and actual roles in decision making among patients with cancer. PubMed (1966 to January 2009), PsycINFO (1967 to January 2009), and CINAHL (1982 to January 2009) databases were searched to access relevant medical, psychological, and nursing literature. Twenty-two studies involving patients with breast, prostate, colorectal, lung, gynecological, and other cancers showed discrepancies between preferred and actual roles in decision making. These groups of patients wanted a more shared or an active role versus a less passive role. Across all cancer types, patients wanted more participation than what actually occurred. Research to date documents a pervasive mismatch between patients' preferred and actual roles during decision making. Yet, there is lack of innovative interventions that can potentially increase matching of patients' preferred and actual role during decision making. Role preferences are dynamic and vary greatly during decision making, requiring regular clinical assessment to meet patients' expectations and improve satisfaction with treatment decisions.

Key words: cancer, decision making, health care participation, patient preferences, systematic review

introduction

Individuals expect and are asked to be involved in health care decisions now more than ever. Over the past 40 years, various influences from ethical, legal, and social issues in health care have caused a shift from being a passive recipient to an autonomous, active, or collaborative participant [1, 2]. This shift has been paralleled by increasing consumerism [3], significant technological breakthroughs in health care [4], and revolutionary transformation in information gathering through the use of the Internet [5].

In the early 1980s, Cassileth et al. [6] reported that studies on patient participation in health care decisions had mainly focused on assessing a patient's preferred level of participation. By the end of that decade, researchers had begun to assess both preferred and actual levels of patient participation. This change in the focus of decision research may have been triggered by an earlier observation of discrepancies between preferred role and actual roles assumed by patients during treatment decision

making [7]. By the early 1990s, the matching of patients' preferred level for participation with actual level of participation had become an important outcome for decision researchers [8–11]. Recently, perceived involvement in decision making has been indicated as a potential mechanism for increasing decision satisfaction, especially among older adults [12].

Today, the process of decision making, particularly patients' preferences for participation, continues to be investigated among patients with breast and prostate cancers. This is largely due to the plethora of treatment options for these cancers with no clear-cut differences in survival outcome. Nevertheless, the number of decision-making studies in patients with colorectal, gynecological, and other cancers has also been steadily increasing. These increases in decision-making studies can be attributed to increasing treatment options as seen in breast and prostate cancers and also because of the initial evidence that individuals who exercise control over decisions regarding their treatment have better outcomes in terms of patient satisfaction [12, 13].

To date, the patients' preferences for participation role during decision making have not been summarized across all

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cancer types to guide clinicians with their patient interactions. This article systematically examines research on both preferred and actual participation in decision making among adult patients with cancer and critically appraises the methods used to measure these constructs.

methods

A systematic review of the research literature was carried out to identify studies that examined decision-making roles such as preferred, actual, or perceived role, and the match between preferred and actual or perceived roles in decision making among patients with cancer. PubMed (1966 to January 2009), PsycINFO (1967 to January 2009), and CINAHL (1982 to January 2009) databases were searched to access relevant medical, psychological, and nursing literature. The medical subject heading terms that were simultaneously used during the search were *decision making*, *patient participation*, and *oncology*. The search was limited to articles concerning adults and English language only. One hundred eighty-eight articles were initially retrieved, and related abstracts were individually reviewed for any report of preferred and actual or perceived participation. If both preferred and actual or perceived participation were reported, full-text copies of the articles were then retrieved and completely reviewed. Of these 188 articles, 34 full-text articles were completely retrieved and reviewed, which yielded 22 studies reporting both preferred and actual or perceived participation in decision making.

A meta-analysis was not attempted due to the descriptive nature of the studies under review. Instead, the studies were classified according to the outcome of interest such as preferred role versus perceived or actual role. The studies were further organized based on the type of cancer diagnosis, presented in tabular form for each type of cancer, and arranged from the oldest to the most recent date of publication. As much as possible, study findings were categorized for interpretability into three levels of participation: active, shared, and passive roles.

Published articles included in this systematic review used the following methods and methodologies:

study designs

Designs commonly used in studies of decision-making preferences include descriptive, correlational, prospective, longitudinal, and cross-sectional or a combination of these study designs. All decision-making studies included in this systematic review examined role preferences descriptively. The three common descriptors of the patient's level of participation in decision making in this literature include active role (autonomous), shared role (agreement with physician), and passive role (leaving decisions to the physician). Some of the studies used a descriptive correlational design, which examined the interrelationships of the independent variables with the outcome variables. All studies used surveys to collect data.

sampling

Convenience sampling was the most commonly used technique in these clinical research studies of role preferences in decision making. This sampling technique can introduce potential selection bias into a study, and the methods, styles, and preferences of treatment decision making commonly used at the institution can influence patient preferences and actual decision-making roles. The advantages of convenience sampling include easy accessibility of subjects, faster accrual, and less expense. Consecutive sampling was used in some of the studies, such that every available subject in an institution was invited to participate in the study. Although there is a similar potential for institutional norms to influence

patient preferences, this is the better choice of the nonprobability sampling techniques because it can result in a good representation of the overall population over a reasonable period of time [14]. The majority of the studies used small sample sizes that precluded exploration of decision-making preferences by factors such as time since diagnosis, cancer type, or demographics. Nevertheless, three studies had large sample sizes to conduct association analyses [15–17].

measures

The Control Preferences Scale (CPS) created by Degner et al. [18] was the instrument most commonly used to elicit patients' preferences for decision-making participation. This scale was developed in response to the challenge of how to measure the degree of control that consumers of health care actually want. The CPS has been two decades in development, beginning with a 4-year qualitative study into decision-making roles in life-threatening situations such as cancer [19]. Four patterns of decision making were identified and described during the initial qualitative study: provider controlled, patient controlled, family controlled, and jointly controlled. The CPS was based on the assumption that patients would have differing preferences about keeping control over treatment decision making, sharing control with their physician, or relinquishing control to their physician.

Overall, the CPS is a clinically relevant, easy-to-administer, valid, and reliable measure of preferred and actual roles in health care decision making among patients with cancer [18]. It has been tested and validated using a card sort procedure on a consecutive sample of 436 newly diagnosed patients with various cancer types seen in ambulatory cancer clinics [11] and using a fixed-order approach with 1012 patients with breast cancer at different points of the disease trajectory [15]. It has also been tested using a random-order approach in a smaller sample of 150 newly diagnosed breast cancer patients [8]. All three of these studies established the reliability of the CPS in cancer patients using Coomb's [20] unfolding theory.

Two studies used investigator-developed treatment decision-making questionnaires. Sutherland et al. [7] and Keating et al. [16] did not report validity and reliability for the five-point Likert-type scales they have used to elicit patient's preferences for participation in treatment decision making. Cassileth et al. [6] developed the Information Style Questionnaire (ISQ) with items designed to elicit data on patient's information and participation preferences. The ISQ had two items designed to elicit patient's preference for participation in treatment decision making. The two statements were as follows: 'I prefer to leave decisions about my medical care and treatment up to my doctor' and 'I prefer to participate in decisions about my medical care and treatment'. The ISQ evolved from a sequence of pilot tests in which 50 additional patients participated. According to the authors, the results of the pilot tests led to the development of meaningful and comprehensible items that were able to discriminate patients' viewpoints. Nevertheless, no psychometric properties of ISQ were reported.

association analyses

Degner et al. [15] found that younger and highly educated women with breast cancer wanted more control in decision making. These findings were also supported by other studies in women with breast cancer [21, 22]. Conversely, Hawley et al. [17] did not find age as a factor associated with more control in decision making, but they reported that patients with breast cancer treated at a facility with American College of Surgeons cancer program were more likely to report active decision making. Keating et al. [16] and Hack et al. [23] reported that patients who were increasingly active in decision making perceived they had enough information and are more likely to report satisfaction with decisions. Potential confounders were not reported except in one study by Hawley et al. [17], which examined between-surgeon effect and within-surgeon effect.

Table 1. Preferred role versus actual or perceived role in treatment decision making

References	Sample size, age range, mean age	Methods: design, sampling, setting; data collection	Patient's preferred level of participation	Patient's actual or perceived level of participation
Sutherland et al. [7]	52 patients, age range not reported, 48.5 years	Cross-sectional, convenience sampling from an ambulatory care facility; survey questionnaires	Doctor alone 32.6%, mainly doctor 30.7%, equal basis 27%, mainly patient 9.6%, patient alone 0%	12 patients did not achieve preferred level, 83% of 12 patients significantly reported an actual level that was less than their preferred
Barry and Henderson [30]	7 terminally ill patients, 18–64 years, 47 years	Longitudinal, series of interviews over 3–8 months conducted at an inpatient unit; mean: 5 interviews	Collaborative with a trend toward active decision making at a later stage	No discrepancy between preferred and actual participation in the early phases of treatment; at a later stage, actual participation was less than patients' desired input
Gattellari et al. [31]	233 patients, 22–82 years, 56.7 years	Prospective, cross-sectional, consecutive sampling from the clinics of 5 medical and 4 radiation oncologists; survey questionnaires	Active 36.9%, shared 44.6%, passive 18.5%	Active 50%, shared 24%, passive 26%
Beaver et al. (1996) [8]	150 patients, 32–84 years, 54.8 years	Cross-sectional, consecutive sampling from one physician's practice; structured interview	Active 20%, shared 28%, passive 52%	Active 15.3%, shared 24%, passive 60.7%
Bilodeau and Degner [10]	74 patients, 18–83 years, 57.5 years	Cross-sectional, convenience sampling from 2 tertiary outpatient oncology clinics; interview schedule	Active 20%, shared 37%, passive 43%	Active 24%, shared 19%, passive 57%
Degner et al. [15]	1012 patients; age range not reported: 29.2% <50, 50.7% 50–69, 20.8% ≥70 years; 58.25 years	Cross-sectional, consecutive sampling from 2 tertiary oncology referral clinics; survey, nurse-administered questionnaire	Active 22%, shared 44%, passive 34%	Active 22.6%, shared 18%, passive 59%
Wallberg et al. [21]	201 patients; age range and mean not reported: 44% ≤50, 36% 51–65, 20% ≥66 years	Cross-sectional, consecutive sampling from an outpatient breast cancer clinic; structured interview	Active 13%, shared 21%, passive 66%	72% agreement between preferred and actual role, 20% wanted more active role, 8% wanted more passive role
Davison and Degner [24]	749 patients; 28.2% ≤50 years, 71.8% >50 years; 58.3 years	Prospective, blocked, two-arm randomized controlled trial from 3 clinics; computer assisted versus interview schedule	Overall: active 31%, shared 49.1%, passive 20%; computer-assisted group: active 34.4%, shared 49.6%, passive 16%; control group: active 27.5%, shared 48.8%, passive 23.7%	Overall: active 28.5%, shared 42.5%, passive 29%; computer-assisted group: active 29.2%, shared 43.3%, passive 27.5%; control group: active 27.8%, shared 41.7%, passive 30.5%
Keating et al. [16]	1081 patients, age range not reported, 57.9 years	Cross-sectional sample selected from previous study participants at 1 study site and from 17 randomly selected hospitals at another; survey, telephone interview	Patient decides: 24.1%, doctor and patient decide together: 63.5%, doctor recommends: 8.9%, doctor decides: 3.3%	Patient decides: 39.8%, doctor and patient decide together: 33%, doctor recommends: 18.5%, doctor decides: 8.6%, note: actual role matched desired role (49%)
Janz et al. [25]	101 patients, 34–81 years, 54.9 years	Prospective, cross-sectional, telephone survey followed by in-person interview; part of a larger intervention study examining the effect of video intervention on making the decision for breast cancer treatment	Active 39.4%, shared 47.5%, passive 13.1%	Active 61.7%, shared 30.3%, passive 8.1%, note: 42.4% agreement between preferred and perceived levels of control

Table 1. (Continued)

References	Sample size, age range, mean age	Methods: design, sampling, setting; data collection	Patient's preferred level of participation	Patient's actual or perceived level of participation
Hack et al. [26]	205 patients; 23.4% <50, 52.7% 50–69, 23.9% ≥70 years; 59.5 years	3-year follow-up study (original study by Degner et al., 1997); survey questionnaires	Preferred role at 3 years: active 35.6%, shared 41.6%, passive 22.8%	Assumed role at baseline: active 27.2%, shared 20.8%, passive 52%
Hawley et al. [17]	1101 patients, 29–79 years, mean age not reported	Cross-sectional, population-based sampling from Surveillance, Epidemiology, and End Results databases; survey questionnaire	Obtained but not reported	Active 39%, shared 38%, passive 22%; note: 66% reported a match between actual and preferred, 21% reported more involvement than preferred, 13% reported less involvement than preferred
Vogel et al. [27]	134 patients, 19–75 years, 53.9 years	Prospective, cross-sectional, consecutive sampling from 2 breast cancer centers; mailed survey questionnaires	Weighted means of baseline, 3 months, 6 months: active 34.5%, shared 24.4%, passive 38%	Weighted means of baseline, 3 months, 6 months: active 35.2%, shared 16.8%, passive 48%
Caldon et al. [22]	356 patients, 30–89 years, 58.5 years	Cross-sectional, convenience sampling from 3 cancer centers; mailed survey questionnaires	Active 40.4%, shared 42.4%, passive 17.1%	Active 64.6%, shared 17.1%, passive 18.3%
Davison and Degner [9]	60 patients, age range not reported, median age 66.5 years	Prospective, two-group, random-assignment, cross-sectional, consecutive sampling from a community clinic; interview	Control group: active 13.3%, shared 50%, passive 36.7%; intervention group: active 36.7%, shared 36.7%, passive 26.6%	Control group: active 16.7%, shared 50%, passive 33.3%; intervention group: active 56.7%, shared 33.3%, passive 10%; comment: intervention group assumed more role than intended
Davison et al. [28]	74 patients with their partners, 40–79 years, 62.2 years	Quasi-experimental, one-group, pretest/posttest, convenience sampling from an outpatient prostate center; survey questionnaire	Active 51%, shared 42%, passive 7%	Active 78%, shared 14%, passive 8%, comment: assumed more role than intended
Davison et al. [29]	324 patients; 44.4% <60, 21% 60–65, 34.6% >65 years; 62.4 years	Randomized, cross-sectional, consecutive sampling from a prostate center; computer-administered questionnaire/survey questionnaire	Control group: active 55.8%, shared 30.3%, passive 13.9%; intervention group: active 50.4%, shared 41.6%, passive 8%	Control group: active 73.8%, shared 16.6%, passive 9.6%; intervention group: active 79.2%, shared 17.5%, passive 3.3%
Hack et al. [23]	425 patients; 16.9% <60, 38.4% 60–69, 42.1% 70–79, 2.6% ≥80 years; 67.4 years	Prospective, cross-sectional; survey, questionnaire—part of a double-blind, blocked randomized controlled intervention trial examining the effect of providing consultation audiotapes on quality of life, mood state, and satisfaction with communication	Preferred role before consultation: active 30.6%, shared 49.2%, passive 20.2%	Assumed role after consultation: active 34.1%, shared 43.3%, passive 22.6%; assumed role 12 weeks after consultation: active 39.7%, shared 31%, passive 28.4%
Beaver et al. [32]	48 patients, 43–83 years, 66.6 years	Cross-sectional, convenience sampling from 1 consultant's practice at a large university teaching hospital; interview schedule	Active 4.3%, shared 17.4%, passive 78.3%	Active 6.7%, shared 13.3%, passive 80%

Table 1. (Continued)

References	Sample size, age range, mean age	Methods: design, sampling, setting; data collection	Patient's preferred level of participation	Patient's actual or perceived level of participation
Ramfelt et al. [33]	55 patients, 34–83 years, 69 years	Prospective, cross-sectional, convenience sampling from 2 surgical units; survey, questionnaires	Active 18%, shared 47%, passive 35%	Active 6%, shared 18%, passive 76%
Davidson et al. [34]	22 patients, age range not reported, 65 years	Prospective, consecutive sampling from 1 outpatient lung cancer clinic; interview schedule	Active 19%, shared 24%, passive 57%	Active 14%, shared 9%, passive 76%
Beaver and Booth [35]	53 patients, 24–82 years, 55 years	Cross-sectional, consecutive sampling from a gynecological service of a large teaching hospital and oncology unit	Active 20.8%, shared 32%, passive 47.2%	Active 22.7%, shared 18.9%, passive 58.4%

results

preferred versus perceived or actual participation in decision making

Studies that have examined both preferred and perceived or actual roles of patients in decision making are outlined in Table 1. Eleven studies involved patients with breast cancer [8, 10, 15–17, 21, 22, 24–27], four with prostate cancer [9, 23, 28, 29], three with various types of cancers [7, 30, 31], two with colorectal cancer [32, 33], one with lung cancer [34], and one with various gynecological cancers [35]. Twenty of the 22 studies used the CPS to elicit the patient's perceived or actual role in decision making. The other two studies used investigator-developed treatment decision-making questionnaires.

All studies showed discrepancies between preferred and actual or perceived roles in decision making. Across all cancer types, the majority of the studies found that patients wanted more involvement initially than what actually occurred (see Table 2). Only 3 of the 22 studies reported that patients' actual participation in decision making increased over the initial preferred level. These three studies all involved patients with prostate cancer. Two of these three studies received a decision support intervention [23, 29], indicating that the intervention had an impact on the patients' level of actual participation in decision making. Patients with various cancers have reported less involvement than what they originally preferred. These groups of patients wanted a more shared or an active role and a less passive role in decision making. Similarly, patients with breast cancer wanted more actual involvement than what they initially preferred, except one study by Janz et al. [25] in which patients wanted less involvement than what actually occurred.

discussion

role preferences

Patients with cancer have large variations in decision-making role preferences, both preferred and perceived or actual roles, with most of the decision-making studies being conducted in breast and prostate cancers. This observation is consistent with Gaston and Mitchell's [13] conclusion in their systematic review on information giving and decision making in patients with advanced cancer. They found that almost all patients expressed a desire for full information, but only two-thirds wished to participate actively in decision making. Unlike this review, Gaston and Mitchell's systematic review also included randomized controlled trials of decision support tools or aids such as question prompt sheets, computer programs, decision boards, audiotape, video, and booklets [13].

The patient's role preference in decision making may also change over time [30, 36]. Patients with colorectal cancer [32, 33] have reported the lowest percentage of active role preference at 6%, whereas patients with prostate cancer have reported the highest percentage of active role preference, as high as 84% [37]. Overall, patients with prostate and breast cancers have reported the highest percentage of shared and active role preferences compared with patients with colorectal, gynecological, and lung cancers as seen in Table 2. Further research on decision-making role preferences of patients with

Table 2. Summary range of patients' preferred role versus actual role by cancer type

Cancer type (N = 19 studies)	Preferred active role (%)	Actual active role (%)	Preferred shared role (%)	Actual shared role (%)	Preferred passive role (%)	Actual passive role (%)
Breast (11)	13–40.4	15.3–64.6	21–63.5	18–43.3	12.2–66	8.1–60.7
Prostate (4)	13.3–55.8	16.7–79.2	30.3–50	14–50	7–36.7	3.3–33.3
Colorectal (2)	4.3–18	6–6.7	17.4–47	13.3–18	35–78.3	76–80
Lung (1)	19	14	24	9	57	76
Gynecological (1)	20.8	22.7	32	18.9	47.2	58.4

cancers other than breast and prostate cancers are needed to better understand these findings.

Among patients with advanced breast and prostate cancers, Gaston and Mitchell [13] reported that active decision making was more common in patients with breast cancer than in those with prostate cancer. Their results are not supported by the findings of this systematic review, which found just the opposite. Active decision making may be more common among patients with prostate cancer than among those with breast cancer, especially those who have received a decision support intervention. This conclusion is generally supported by the recently published Canadian studies on decision-making preferences among patients with early-stage prostate cancer [37–40]. Based on these studies, it is unclear whether the time since diagnosis (newly diagnosed versus late and advanced cancer) plays a role in patients' preference for less passive and more active involvement.

A mismatch between patients' preferred and actual roles was common in the studies reviewed. The majority of the patients did not realize the role they desired. This finding indicates that regardless of the stage of cancer or time since diagnosis, predicting an individual's preference, instead of determining it directly, often leads to a miscalculation of a patient's desired role. This distinction is a key consideration clinically and in research, given the preliminary evidence that perceived role may predict decision satisfaction [12]. Clinicians need to avoid predicting their patients' role preference and start providing patients with an open communication climate that allows them to achieve their desired level of participation during decision making. A simple screening regarding patient's role preference can be beneficial and promote cooperation between the clinician and the patient. Clinicians should also conduct a follow-up assessment of patients' preferences for participation in decision making because of the dynamic nature of role preference.

A prospective longitudinal design is desirable for any future decision-making studies to examine the stability of a patient's role preference and capture its dynamic nature. A design that has not been used in the study of patient's role preferences in decision making is a model testing design, which would be specifically designed to test the accuracy of a hypothesized causal model with measurement of all variables relevant to the model [41]. This next step in decisional role preferences research may be helpful for understanding the complex nature of health care decision making.

limitations

Although this review covers a substantial number of studies on patient participation in decision making with various cancer

diagnoses and conducted in different clinical settings, the authors recognize certain limitations. First, unpublished dissertation studies were not included in the search. Second, other database searches using such resources as Google Scholar or Web of Science were not included. Finally, studies included in this review were only those in the English language and were conducted in the United States, Canada, and the UK, countries with documented increasing health care consumerism. This limits the generalizability of our findings particularly to countries where paternalism remains the dominant model of patient–provider relationships and may be associated with patients preferring a more passive role in decision making.

conclusions

The descriptive nature of the studies included in this review makes it very difficult to calculate the exact difference between preferred and actual roles in decision making; hence, the authors report a summary range. Nevertheless, despite the use of a summary range, it is still quite clear that there is a limited concordance between preferred and actual roles in decision making. This limited concordance between patients' preferred and actual roles assumed during decision making has indicated that clinicians need to raise their sensitivity regarding patient's participation in health care decisions. Given the variability and dynamic nature of patients' role preferences, an individual assessment should be carried out during the entire course of treatment planning, particularly each time a critical treatment decision is about to be made. There is a need for clinicians to improve their communication skills to promote a patient's willingness to share his/her needs and desires. Innovative intervention studies that can improve matching of patient's preferred and actual roles during decision making are warranted as are studies that examine clinicians' views on patient participation in decision making. Research on how patient- and clinician-related characteristics affect treatment decisions (e.g. age, gender, race/ethnicity, education) is also needed to determine those factors that affect the actualization of patients' preferred role.

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disclosure

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